



# CRS Parent Connection

Alabama Department of Rehabilitation Services



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Winter 2009

## Maternal and Child Health Needs Assessment: We need your help!

It's Needs Assessment time again! As some of you may know, each year states apply to the federal Maternal and Child Health Bureau (MCHB) for Title V MCH Block Grant funds. These funds are provided through Title V of the Social Security Act and are used by states for programs and policies that improve the health of women and children, including children and youth with special health needs. To make sure that programs are responding to issues that are important in local communities, each State Title V Program is required to complete a needs assessment every five years. This answers questions about health and related services that families in the state may need, and especially looks at strengths and gaps in the system. Information gathered helps the state set priorities and plan programs that better meet the needs of children and families.

Children's Rehabilitation Service (CRS) partners with the Alabama Department of Public Health to complete the Title V MCH Needs Assessment for Alabama. CRS focuses on the parts related to children and youth with special health care needs. Although the final report isn't due until July 2010, we are now starting to plan how we will gather information and how we can best get input from children and youth with special health



*Gwen Weed, CRS supervisor, reads to consumer Lydia Casady in the Mobile CRS office. Soon, CRS will be seeking input from consumers and families about whether CRS services are meeting families' needs. CRS is planning several focus groups and surveys with families, youth, and target care providers*

care needs and their families. **WE NEED YOUR HELP!**

CRS will be working with Family Voices of Alabama and the University of Alabama at Birmingham School of Public Health to conduct our part of the needs assessment. We are planning several focus groups for families and youth and also several surveys. Some surveys will target care providers, but others will focus directly on families

who have children with special health care needs and on youth with special health care needs. We really want to reach as many Alabama families and youth as possible! These surveys will be available in hard copy in locations near you, but you will also be able to take them online. Please watch your email, newsletters, and any listservs you belong to for more information about how you can take the survey. We'll provide a link to take the survey online and more information about where you can get a hard copy, if you'd prefer. Also, we will be recruiting families and youth for the focus groups, so there may opportunities for you to participate if you're interested. Look for that information as well.

We are so excited about looking at Alabama's system of care for children and youth with special health care needs. We want to partner with you to help our state continue to improve and better meet your needs. Your input is invaluable to the process! If you have any questions about the needs assessment or would like more information on the plans so far, please call Julie Preskitt at 1-800-441-7607 or by email at [julie.preskitt@rehab.alabama.gov](mailto:julie.preskitt@rehab.alabama.gov).

**Julie Preskitt, MS, OT, MPH**  
*Special Programs Coordinator*

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## CRS Parent Connection

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*Parent Connection* is a complimentary newsletter published by Children's Rehabilitation Service for families of children with special health care needs. The goal of this newsletter is to increase communication and share information about children with special health care needs and their families. The newsletter reflects a family-centered theme throughout and serves as a forum for family members to share information, thoughts, feelings, concerns, etc. Nothing printed or implied in this publication constitutes an endorsement by the Alabama Department of Rehabilitation Services.

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# From the Director's Chair



Hello, Parents and Caregivers,

We are facing a time of **significant change** at ADRS – change in leadership and change in our fiscal planning and budgeting. Through it all, our focus remains on providing quality services to you and the loved ones you care for each day. You might recall that the fall 2008 newsletter featured a special message from Commissioner Steve Shivers saying goodbye after many years in rehabilitation, the last nine of which were spent leading this agency. He retired as planned on Dec.31 and since that time, our Chief Financial Officer Winona Nelson has been serving as interim commissioner.

With all of the talk and discussion of tough economic times nationwide, I am sure you have been closely monitoring the financial climate of our state and particularly, this agency. Gov. Bob Riley recently released his recommendations for Education Trust Fund and General Fund appropriations for FY 2010. Due to the economic downturn, his total recommendation for all ADRS programs is about \$7 million dollars less than in FY 2008. I will walk you through the last three fiscal years of fluctuating budget changes for Children's Rehabilitation Service (CRS):

- In FY 2007, CRS received \$600,000 less than requested.
- In FY 2008, CRS received all that we asked for, including the shortfall from FY 2007.
- For FY 2009 (the current fiscal year), CRS received an allocation very similar to the 2007 level (a reduced amount from 2008).
- In December 2008, ADRS received notification that all of our programs would be prorated by 9 percent. This decreased reduced the FY 2009 allocation even further.
- The recommendation for FY 2010 is 2.93 percent less than the 2009 prorated amount.

In simple terms, the CRS allocation has decreased significantly since FY 2008. The total reduction from 2008 to 2010 could be as much as \$3.8 million. So, as you meet with community leaders and legislators about CRS, here are some facts that may be helpful to you:

- In FY 2008, CRS served 12,388 children and 306 children and adults with Hemophilia.
- Health care costs are continuing to rise, therefore increasing the cost of providing services.
- Federal funding to CRS has decreased steadily over the past few years.
- Staff shortages (due to the hiring freeze) adversely effect the timeliness of providing services, quality of care, and our ability to assist local school systems with screenings, consultations and other services.

Please continue to listen to news reports and to read newspapers and other articles to stay up to date on legislative activities. If you have questions about how things are going for the agency or about ways that you might be able to assist, please contact our state office at (334) 293-7500 or 1-800-846-3697. You may also call your local CRS office or parent consultant.

We look forward to continuing to provide quality services to you and all of our families in communities across the state.

**Melinda M. Davis**  
Assistant Commissioner, CRS

# CRS Consumer Spotlight: *Justin Wallace*

*Parent Connection* is launching a new section of the newsletter that highlights the accomplishments of Children's Rehabilitation Service (CRS) consumers. Accomplishments highlighted may include academic, social or "just surviving."

If you want to include the accomplishment of your child or a CRS consumer you know in the next newsletter, please send a photo of the child in his or her "element," and a summary of why the consumer should be featured in the "CRS Consumer Spotlight" section to Susan Colburn at [susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov). If your recommendation is chosen, please be prepared to answer a series of questions about the child's favorites.

The new section is the idea of Cynthia Murphy, traumatic brain injury care coordinator for CRS, who has recommended the first consumer to be spotlighted:



*Justin, number 35, relaxes during a time-out while playing a game of wheelchair basketball*

Justin Wallace was nominated to "CRS Consumer Spotlight" because of his ability to go from tragedy to triumph. After a motorcycle accident at 15 years old left him paralyzed below the waist, Justin experienced a series of medical complications and surgery, requiring total bed rest, and homebound education for

many months. Now recovered two years later, Justin has returned to school, passed a driving evaluation and is playing wheelchair basketball with Lakeshore Foundation. He credits his successes to his supportive family and friends who have "hung" with him throughout this process.

## 2009 New Year's resolution for family caregivers

The National Family Caregivers Association suggests the following New Year's resolution for all family caregivers: Make 2009 the year you SPEAK UP. NFCA encourages and stresses the importance of arming yourself with vital information regarding your loved one's condition and your rights to information. Knowing how to communicate with health care professionals is a critical step in beginning to advocate for yourself and your loved one.

Joining our NFCA community of caregivers can be your first step in reaching out for information, support and resources, and – in the process – becoming an empowered family caregiver. Joining is always FREE to family caregivers.\* You will immediately receive a host of educational materials in your welcome

kit, a subscription to the quarterly *Take Care* newsletter, and NFCA's monthly e-letter filled with new ideas and resources. Start SPEAKING UP for yourself today and join NFCA ([www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)).

SPEAKING UP in 2009 also includes understanding that today caregiving is much more than a personal family issue. It is the issue of our age because sooner or later caregiving will affect every family in America, and we are not prepared either as individuals or as a society to deal with it. YOU can make a difference in SPEAKING UP for public policies that impact the quality of your life. We have an opportunity now that we haven't had before to make our health care system responsive to the needs of individuals with chronic conditions, improve

care and cut costs. We and our loved ones are the critical piece in health care reform. Helping family caregivers helps everyone. Remember, there is power in numbers; 1 out of every 5 Americans is a family caregiver. For ideas on how to YOU can make a difference, visit NFCA's Advocacy outreach page.

And you can SPEAK UP for family caregivers through NFCA by helping us to reach as many family caregivers as possible with our outreach, materials and programs. A donation today to NFCA makes it possible for us to SPEAK UP with a louder voice on behalf of you and all of America's family caregivers. We are grateful for any donation to NFCA.

\*Professionals, organizations and companies are welcome and encouraged to join us.

Please add me to your newsletter mailing list.

Name: \_\_\_\_\_

Agency: \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Clip and mail to  
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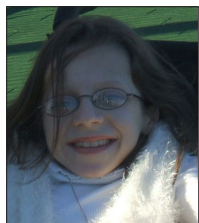




# Opelika opens miracle field for local children

On a recent sunny, windy winter day in Opelika, a big red ribbon floated to the ground, signifying the completion of The Billy Hitchcock Miracle Field.

The city of Opelika earned a “big kudos” from local children with disabilities, who now have a place to play the game that America loves.



**Danielle**

It all started with the dream of a young girl named Danielle Tadych, who wished for a smooth surface, a place for kids like her to play baseball. There was also the inspiration of Dr. Todd Shields and his family, who started the Challenger league. The help of Opelika residents also contributed to creation of the largest accessible ballpark in the country.

The new park includes several accessible bathrooms, picnic tables, and an absolutely beautiful boundless playground for all children. The playground's design was created with guidance from the Opelika CRS office, particularly Occupational Therapist Debbie Daniels.

The Lions Club of Opelika took on this project with the hopes of making the game of baseball a little easier and “trying to give back



*Opelika residents participate in the ribbon-cutting ceremony of the Billy Hitchcock Miracle Field*

to people who deserve a little more joy,” said Rob Cox, chairman of its board.

The Miracle League of East Alabama field is one of six in the state. Registration has begun for the upcoming season, please see accompanying listing for a league in your area.

**Sharon Henderson,**  
*Parent Consultant, Opelika*

## ALABAMA MIRACLE LEAGUES

### CULLMAN

[www.cullmanrecreation.org](http://www.cullmanrecreation.org)  
Shelby Williams, 256-739-9931

### DOTHAN

Larry Patrick, 334-615-3700

### HUNTSVILLE

[www.huntsvillemiracleleague.org](http://www.huntsvillemiracleleague.org)  
[johnny@miracleleague.org](mailto:johnny@miracleleague.org)

### MONTGOMERY

[www.mtgml.com](http://www.mtgml.com)  
Kerry Cherry, 334-300-1088

### MOODY

[www.moodymiracleleague.com](http://www.moodymiracleleague.com)  
Phillip Deason, 256-739-9931

### OPELIKA

Rob Cox, 334-749-3371

**Currently in process of raising funds for fields:** Gardendale, Jasper, Scottsboro, Troy, Tuscaloosa



*The miracle field in Opelika includes this accessible playground for children with special needs*

For information about the Miracle League in Alabama, call 256-562-1272.

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## ***CRS Family Stories:***

# **Mother proud of daughter's accomplishments**

Hello, CRS families. My name is Natalie Portera. I have been happily married for 16 years to Danny Portera. I am very blessed to have two wonderful daughters, 8 and 12 years old. My 12-year-old, Danielle, is an honor student and in her tenth year of dancing. She also plays the violin, plays volleyball, and is a Girl Scout.

I would like to tell you about the wonderful accomplishments of my 8-year-old, Dominique. She is in the second grade at Gwin Elementary. She is in her sixth year of dance this year. This past June she received her five-year dancing award from Dale Serrano.

She has been very fortunate to take dancing with her typical peers. This has been great physical therapy for her. She attends Prince of Peace Catholic Church and is in her age-appropriate Sunday school class. She made her First Communion last May, which is really a big deal in our church. She knows Jesus loves her and made her perfect. Prince of Peace Church has a support group for parents of children with special needs. This group tries

to meet once a month for a social gathering. If you are interested in attending, please email me at [atdownisup@aol.com](mailto:atdownisup@aol.com).

Dominique is learning to read this year and has some wonderful peer helpers in her class. She has made some real friends at school and they even enjoy getting together to play outside of school. She loves school, dancing, and anything Hannah Montana.

By the way, did I mention she also has Down syndrome? To me, having Down syndrome makes you more of a real person. People with Down syndrome do not have any fake qualities. What you see is what you get. Individuals with Down syndrome do not try to hide things in conversation. They speak from the heart. They do not have the judgmental qualities that some of us have. They love you completely for who you are. With my daughter having Down syndrome, she has opened my eyes to many small blessings. Our family can rejoice in all accomplishments, no matter how small. I am so proud of both my daughters and I would not change a thing about either one of them.



*Dominique Portera, 8, practices dancing, which is great physical therapy for the youngster, who has Down syndrome*

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## **Cheerleading brings confidence to child with special needs**

If you met our daughter Ashlee for the first time, you might think she is just an extremely shy, 9-year-old little girl. Hang around long enough, though, and you will pick up on her special needs and different abilities. Outside the privacy of our home, few had the joy of seeing her in action – singing, dancing, jumping – that is, until this past year.

We began homeschooling Ashlee in June. Knowing her love for “High School Musical” and “Camp Rock,” I began searching for some way to get her involved in a dance-type activity that would allow her to fellowship in a peer group but also help her showcase her “secret” talents outside our home. I happened across ACE All-Stars of Alabama’s website and their Bows and Arrows special needs team. Only minutes after requesting information by e-mail, Coach Bill Presson responded with an invitation to check



*Ashlee Sellers*

her new friends and in her new sport. Typically, Ashlee had always been on the sidelines of her older sister’s activities. Now her sister Catherine is cheering her on instead.

The team meets once a week and practices

them out. The professional and compassionate coaching staff was so welcoming to Ashlee and so patient with her hesitation to join them. Surprisingly, it wasn’t long before she was comfortable with

in the same gym alongside other ACE All-Star teams. They have already competed at three large competitions and are heading to Atlanta for national championships. Ashlee doesn’t hold back. She is comfortable and confident performing on stage, even with all the screaming folks in the audience cheering them on. Her newfound confidence has even trickled into other areas of her life and given her a sense of independence.

This is a dream come true for Ashlee, and with other cheerleading gyms offering and creating these wonderful special athletes teams, more dreams will soon be fulfilled – both for the athletes and their parents!

**Amy Sellers**  
*Parent*



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# *The Catalyst Center: A catalyst for change*

## Responding to the challenges of health-care financing

According to the 2005 survey of children and youth with special health care needs (CYSHCN), approximately 12 percent of CYSHCN lack health coverage, and many more are underinsured. Access to adequate, cost-effective health insurance is a major concern for all families, especially those with CYSHCN. Complex challenges also confront those working on the other end to improve health-care financing for CYSHCN. Financing options vary from state to state, and although programs such as Medicaid and SCHIP have a federal base, each state implements federal policy differently. The health-care environment in each state can be affected by factors such as demographics, private/public payer mix, cost of living, employer mix, race, and age. Stakeholders in each state may have their own perspective about the meaning of cost-effective, accessible health-care coverage.

This is where the Catalyst Center ([www.hdwg.org/catalyst/](http://www.hdwg.org/catalyst/)) comes in. The center provides technical assistance and research support to states and communities for improving health-care financing to meet the diverse needs of CYSHCN and their families. Meg Comeau, project director, sees the role of the center as a catalyst to states by gathering information about individual state models and providing basic tools and resources to help each state make their own important changes in health-care financing and insurance coverage.

The Catalyst Center's objectives are:

1. Cover more kids: Increase the percentage of children covered by health insurance
2. Close benefit gaps: Reduce underinsurance
3. Pay for additional services: Improve payment for important services, such as respite care and care coordination that insurance generally does not cover
4. Build capacity: Enhance funding for the CYSHCN health infrastructure

### **Health Insurance & Financing Toolkit: Tools You Can Use**

The multidisciplinary team at the Catalyst

Center creates and disseminates information in response to the interests and requests from a broad range of stakeholders, including families, providers, advocates, state Title V and Medicaid program staff, and health insurers.

Drawing from different areas of expertise, this talented, five-person group has created technical briefs on many topics, including Catastrophic Relief funds for CYSHCN, Medical Debt ("Payer of Last Resort"), and the Family Opportunity Act's Medicaid buy-in option. A recent publication, "Designing Evaluation Studies of Care Coordination Outcomes for Children and Youth with Special Health Care Needs," ([www.hdwg.org/resources/toolkit/designing-evaluation-studies-care-coordinationoutcomes-children-and-youth-special](http://www.hdwg.org/resources/toolkit/designing-evaluation-studies-care-coordinationoutcomes-children-and-youth-special)) responds to a concern from stakeholders about how to sustain the use of care coordinators within the medical home. Care coordinators exist in various forms in states and communities, and there is an increasing need to evaluate the cost/benefit of investing in them. This publication provides stakeholders with a guideline for creating their own customized evaluation study that responds to the variability in care coordination activities between and within different organizations, rather than giving formulaic instructions.

### **Data, Innovation, and Inspiration**

The Catalyst Center's State-at-a-Glance Online Chart Book ([www.hdwg.org/catalyst/chartbook](http://www.hdwg.org/catalyst/chartbook)) on Coverage and Financing of Care for CYSHCN helps users gain a better understanding of the health-care financing system and learn from the innovative practices occurring in other states. It allows states to access their state page and compare it with other states. Simple and easy to use, the online chart book provides helpful tips on how to understand and apply the data. The "Get Inspired" section includes descriptions and samples of interesting state practices with a focus on implementation and innovation. The chart book contains information gathered from various sources, including state Title V

leaders, Medicaid staff, members of Family Voices ([www.familyvoices.org](http://www.familyvoices.org)) and the Family to Family Health Information Network ([www.familyvoices.org/projects/f2f.php](http://www.familyvoices.org/projects/f2f.php)), Child and Adolescent Health Measurement Initiative (CAHMI) Data Resource Center ([www.childhealthdata.org](http://www.childhealthdata.org)), and the U.S. Census Bureau.

Another interactive way for individuals to gain immediate technical assistance from the Catalyst Center is to participate in a Topical Conference Call. The Catalyst Center is always open to suggestions on topics. The schedule of calls can be found on its website.

### **Families: The First Line of Defense**

While gathering information for the Chart Book, Ms. Comeau reported that families provided an enormously helpful "reality check" for the Catalyst Center. Families were interviewed about the content, and the information was returned to the interviewees for accuracy before it was published. Now that the Chart Book is online, it is easily updated with accurate, up-to-date information. The review committee for the chart book included eight people, four of whom were parents of CYSHCN. Every effort is made by the Catalyst Center to deliver tools and resources that can help families make informed decisions and actively participate in improving cost-effective, high-quality care on the policy level.

The Catalyst Center continually strives to promote this standard for the health-care system by providing its stakeholders with high-quality tools and resources needed to ensure that families of CYSHCN have adequate access to public and/or private insurance to pay for services they need. For more information, contact:

**Meg Comeau, M.H.A., project director**  
The Catalyst Center  
Health & Disability Working Group  
374 Congress St., Suite 502  
Boston, MA 02210  
617-426-4447, ext. 27  
[www.hdwg.org](http://www.hdwg.org)

# Book Review:

## "More Than a Mom"

"More Than a Mom: Living a Full and Balanced Life when Your Child has Special Needs," by Heather Fawcett and Amy Baskin, is a "must-read" for all mothers of children with disabilities.

Often the endless appointments, phone calls, meetings and advocacy we constantly face can cause us to cut short the time we spend on other things. We might be wondering, "What about my marriage?" or "Can I maintain my career?" or "How do I ever

find time to have meaningful friendships?". This book answers those questions and more. The authors, two moms of children with special needs, talked with more than 500 moms of kids with all kinds of special needs, and became inspired by their creativity and determination, and that is what is represented in this book.

This book has received seven five-star reviews on Amazon.com, including the following:

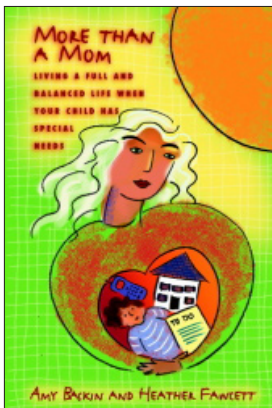
"This book is awesome! It is helping me realize I need to take more time for myself and the rest of my family. I highly recommend this book for any parent of a child with special needs."

"It's so refreshing to read a book that focuses on positive, real life needs of families. I found every chapter to have useful, realistic information for parents and professionals alike. Well done!"

Check out this book at the Resource Center in your local CRS office.

**Vonda Reeves**

*Parent consultant, Dothan*



find time to have meaningful friendships?". This book answers those questions and more. The authors, two moms of children with special needs, talked with more than 500 moms of kids with all kinds of special needs, and became inspired by their creativity and determination, and that is what is represented in this book.



*A Camp Smile visitor enjoys a horseback ride as staff provide assistance*

## Camp Smile offers summer fun

The summer camp experience is about much more than horseback riding, paddleboats, and swimming in the lake. For young people across America, summer camp is a stepping stone on the road towards independence.

Nowhere is this more true than at United Cerebral Palsy's Camp SMILE, an inclusive summer camp for individuals with and without disabilities. Here, campers not only have the chance to participate in physical activities like tee-ball, fishing and horseback riding; they also meet dozens of others whose abilities and life experiences are

similar to their own.

UCP offers four sessions of Camp SMILE:  
 June 16-20, 2009 ..... 9-15 year-olds  
 June 23-27, 2009 ..... 3-8 year-olds  
 July 7-11, 2009 ..... 16-24 year-olds  
 July 14-18, 2009 ..... 25 years old & up

All four sessions of Camp SMILE are held at Camp Grace, a privately owned and operated property on over 220 acres in West Mobile.

*For more information on Camp SMILE you may visit our website: [www.campsmilemobile.com](http://www.campsmilemobile.com) or contact Cecy Lowell at (251)479-4900 or by email at [clowell@ucpmobile.org](mailto:clowell@ucpmobile.org).*



**Left:** Three campers enjoy a paddleboat ride on the water. **Above:** A camper takes a swing during a ball game.



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# CRS staff participate in spina bifida bowl-a-thon

The Spina Bifida Association of Alabama (SBA of AL) recently held its second annual bowl-a-thon at Paradise Lanes in Gadsden.

This bowl-a-thon was organized by Angie Pate, mother of Cameron Pate, who was born with spina bifida and is a Children's Rehabilitation Service (CRS) consumer in Gadsden. Gadsden CRS has bowled in both bowl-a-thons while this was the first time for the Anniston office.

Since I became more active in the SBA of AL due to my daughter, Lana, who was born with spina bifida, I asked the Anniston office to participate this year. To my surprise, Anniston CRS had enough volunteers for two teams!



*Staff from the Anniston and Gadsden CRS offices pose for a picture at the bowl-a-thon*

These events are held around the state and provide a fun time for families to meet and socialize while raising funds for the SBA of AL. It also increases community awareness of spina

bifida and its prevention.

There were 150 bowlers filling all lanes of the bowling alley at the Gadsden event, and a total of \$11,862 was raised.

If you are interested in being on an SBA of AL bowl-a-thon planning committee or in hosting a bowl-a-thon in your city, please contact Angie Pate at 256-295-0757.

If I can assist anyone in any way, please contact me at 256-235-3050, 1-800-289-9533 or [sandra.hazzard@rehab.alabama.gov](mailto:sandra.hazzard@rehab.alabama.gov).

**Sandra Hazzard**  
*Parent Consultant*  
*Anniston, Gadsden, Talladega*

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## Mark Your Calendars

### Spina Bifida Conference discusses transition - Oct. 9, 2009, in Birmingham

"Transition" is such an important word in the life of an individual with spina bifida. The truth is that a family affected by spina bifida has to begin thinking about issues related to transition from the time of birth of their child. So what exactly does this word mean? According to Webster's dictionary, it is a passage from one form, state, style, or place to another. For an individual with a disability or for those who have a child with a disability, it means much more. It is a word that will become an integral part of each stage of his or her life.

Often we hear about the importance of a young adult with a disability finding the medical, social, and economic resources needed to transition independently into adulthood. It is just as important to learn more about the many transitions an individual with a disability and the family endure from birth to adulthood. Two examples of issues related to transition for an individual with a disability are educational and medical transitioning.

Beginning with preschool and throughout high school, it becomes necessary for a parent of a child with special needs to communicate with teachers, principals, school nurses and counselors within the educational system. Communication needs to be clear between

the parent and the school system to make sure that the child has all his or her special physical and educational needs met. For instance, teachers and school nurses need to keep a latex-free environment if they have a child with spina bifida. Also, it can be very frustrating for the parent, teacher and student when the child faces learning challenges. It takes a great amount of patience to deal with this process, but even more frustrating for the parent. It seems as soon as the child's school has a good grasp of the child's special needs, it is time for the child to once again transition to another school.

Medical professionals are always working to help the child reach new levels of independence. This is another very important transition factor. It is the goal of every medical professional who cares for an individual with spina bifida to help the patient reach the greatest level of independence possible. To do this, they have to help the families make very important decisions, such as the right time for the child to begin catheterizing independently, what home modifications need to be made to create the safest environment, and when and how the individual should begin driving.

There are many resources available to parents and caregivers of individuals with special needs

to help ease the process of transitioning. To learn more about these resources and the different stages and issues associated with transition in the life of an individual with spina bifida, be sure to attend the Spina Bifida Association of Alabama (SBA of AL) and The Children's Hospital in Birmingham's learning conference titled, "Bridges to Independence," on Oct. 9, 2009, from 8 a.m. to 3:30 p.m.

Topics will include:

- Accessibility and home modification
- Transitioning through the medical system and how it relates to the health care worker and parents
- Transitioning through the educational system
- Driving – how to be referred, evaluated and obtain vehicle modifications

There will be a panel of adults with spina bifida available to answer any questions related to their personal transition experiences.

*For questions about this conference, contact Betsy DeCesare at 205-939-528, [betsy.deCesare@chsys.org](mailto:betsy.deCesare@chsys.org) or Angie Pate at 256-295-0757, [angie.pate@gmail.com](mailto:angie.pate@gmail.com).*

*\*CEU credits will also be offered to medical and educational professionals.*



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# FAMILY VOICES

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## Providing input to the new administration - family-to-family style

It is the start of a new year and a new administration in the White House.

President Barack Obama has made it clear he is seeking input from the people about issues that concern all of us, and Family Voices is stepping up to the plate. Parent leaders from across the country, individually and collectively, are taking the administration up on the offer and making sure that the voice of the families with children and youth with special health care needs (CYSHCN) is heard.

**Doreen Hodges, Executive Director of Family Voices of DC and the DC F2F HIC**, recently taped a two-minute TV commercial to be aired around the time of the inauguration. She sought – and received – input through the FV-Talk network. Her statement, in addition to raising awareness about the work of Family Voices and the F2F HICs, focused on what “change” means to families of children with special health care needs.

**In North Carolina, the Exceptional Children’s Assistance Center, home to the NC F2F HIC**, recently called a town meeting-style “Health Care Initiative Forum.” They invited interested parents and professional partners to discuss health-care reform and to draft a report to send to the new administration. Twenty-six attendees discussed the state of health care today in North Carolina, and the complex issues and obstacles that must be overcome in order to “fix” its problems. They noted especially that the current health-care system structure, combined with high cost, and limited access, helped create the problems – and to perpetuate them.

**In Utah, Gina Pola-Money, of the Utah Family-to-Family Health Information, Education, and Support Center**, gathered information from families across the state and provided comments and feedback about the needs of Utah’s CYSHCN to state and federal elected officials.

**There are obviously a multitude of ways** to ensure that the needs of CYSHCN are adequately considered in the new administration’s health-care reform discussions. Up until the inauguration, input could be shared online with the Transition Team. Now, you can share your concerns and ideas at [www.whitehouse.gov/administration/eop/opl/](http://www.whitehouse.gov/administration/eop/opl/)

How input is provided is less important than making sure the input is given. This is a critical time to raise family voices all across the country as changes in health-care systems are debated.

### Resources

#### *Family-Centered Care Tools*

Originally featured in the November 2008 edition of *Friday’s Child*, these newly-published Family-Centered Care Self-Assessment Tools are designed as an opportunity for health-care practices and families to assess current areas of strength and identify areas for growth, plan future efforts, and track progress toward family-centered care. These tools include a Family Tool, a Provider Tool, and a Users Guide. An online feedback survey will soon be available for you to give input to help us to continue to improve these tools. For more information, please visit the FV website.

### News You Can Use

#### *Resources and More For Families*

#### **United Health Care Children’s Foundation Medical Assistance Grants**

The United Health Care Children’s Foundation offers parents and caretakers up to \$5,000 in grants to help cover medical services to improve the health and quality of life of their children.

These grants can be used for such services as speech therapy, physical therapy, and psychotherapy sessions; medical equipment such as wheelchairs, braces, hearing aids, and glasses; and orthodontia and dental treatments.

Children up to age 16 and living in any of the 50 states are eligible for a grant. Families must meet economic guidelines, live in the U.S., and be covered by a commercial health plan.

Visit the United Healthcare’s website for more information.

#### **CDC “Learn the Signs. Act Early” Campaign**

Parents often assess their child’s development by physical milestones, such as sitting independently or taking first steps. A new campaign by the Centers for Disease Control and Prevention (CDC), entitled “Learn the Signs. Act Early,” encourages parents to look for social milestones, such as smiling, making eye contact, and playing with others. Delays in these markers might be an early sign of a development problem such as autism.

Check out the website, which you can access from the Family Voices website or directly on the CDC website.

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For information about Family Voices, please contact the Alabama state coordinators, Susan Colburn (334) 293-7041, [susan.colburn@rehab.alabama.gov](mailto:susan.colburn@rehab.alabama.gov) or Jerry Oveson (251) 438-1609, [oveson@bellsouth.net](mailto:oveson@bellsouth.net).

# CRS sponsors transition expo

The Anniston, Gadsden and Talladega CRS offices recently held a teen transition expo at the Gadsden Senior Activity Center. More than 200 teens with disabilities attended the expo.

John Croyle, founder and executive director of Big Oak Ranch, was the keynote speaker.

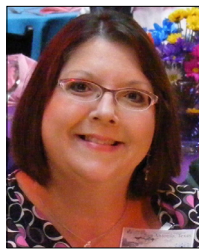
Speakers were also on hand from Gadsden State Community College and the Gadsden Career Center. More than 20 exhibitors provided information to assist teens with disabilities with the transition into adulthood. The event was a great success.



*John Croyle, founder and executive director of Big Oak Ranch, speaks at the transition expo in Gadsden*

## Funderful Times – *Healthy & Happy*

These days, I am focused on living healthy, which will lead to well-rounded happiness. At first, I must admit, this was not an easy task for me. I would rather stick my hand in the cookie jar for a chocolate chip cookie than slice an apple or peel a banana. However, being diagnosed as a potential diabetic and having arthritis in my neck and spine woke me from a dreamy laziness. I began to look for ways to eat healthier and exercise even though my abilities are limited at this time.



**Cobbs**

Consider these steps to having a healthy and happy life:

- Purchase fresh fruits and vegetables you enjoy eating. Prepare them by cleaning, peeling, and placing them in single serving sandwich bags ready to eat and premeasured. Salad mixes work great for this also.
- Swap from whole milk to fat-free milk by pouring half of each in a glass and mixing them together. Slowly use less of the regular milk and swap to fat-free milk. This will also cut your grocery bill since fat-free milk is often

cheaper. Thus, you will get fewer fat calories in a glass of milk, but still achieve the daily calcium needed for your bones.

- Bundle up for some fresh air and walk around the perimeter of your yard or apartment parking lot. Add a lap each day so that you get some exercise. Partner with a co-worker for accountability and walk together during breaks.

• Eating out? Not for my family. I purchase groceries online using [www.schwans.com](http://www.schwans.com). The items are large and cost-efficient for my family. If I count the cost of time and gas it takes to go to the grocery store, I save a lot of money this way. Plus, I don't buy what I don't need. Home delivery for this company is \$1. For other online grocery stores, the costs are no more than \$12. That is less than the price of gas these days.

- Shower with warm water, but just before getting out, switch to cold. This will not only wake you up, but give you a boost of energy. Rinsing your hair and face in cold water will give you a shine and a glow (now you know my secret).

• Recycle. This will give you a feeling of saving the earth and the future. It's a simple satisfaction.

• Read. The Bible is good for spiritual renewal every day or an encouraging devotional will lift your spirits. Reading positive words of encouragement will bring self-awareness.

• Try Yoga or relaxation meditation. This will give you an opportunity to regroup and focus, especially if done before bed. It will give you restful sleep.

• Is your sleep disrupted? You might consider seeing a sleep specialist to help with natural ways to get a better night's sleep. Also, consider listening to soft classical or relaxing music before going to sleep. I count from 100 backwards until my continuous positive airway pressure (CPAP) machine starts working. (Now you know my other secret). With asthma, I never slept well until I was evaluated in a sleep study.

• Get your eyes, teeth, and hearing checked on a regular basis along with a yearly physical. It will be money well spent for a year of good health.

These are simple steps toward better days of health and happiness.

**Rita Cobbs**  
*Parent, Huntsville*





## Let's YAC About It

### Site targets Alabama's young adults with disabilities

Brian Burrows, YLF steering committee member and Young Adults in Transition (YAIT) facilitator, has developed a social networking site for young adults with disabilities. The site is called "My Voice," and is hosted by Ning, which lets people create their own social networking site. Along with friend and fellow committee member Matt Haynes, Burrows hopes to bring together young adults using the power of the Internet.

My Voice has many great features to allow members to connect, including posting comments to personal pages, joining in on discussions, and viewing videos and pictures.

My Voice also hosts regular chat sessions on various issues such as disability history, employment, dating, or whatever the members desire.

The target audience for My Voice is young adults with disabilities, 16 to 30 years old, and living in Alabama. The site is being developed as a community that creates informal and relaxed mentoring relationships that flow naturally like other social networking sites do. Haynes and Burrows will assign high school youths to experienced My Voice members who are successful young adults. Those young adults will encourage high school student involvement

in My Voice activities such as chats and message boards. My Voice is always seeking more young adults with valuable life experiences to share to serve as mentors. Burrows, along with along with YAIT members, plans to present the developments in a pre-conference workshop at the 2008 Transition Conference.

To protect the confidentiality of its members, joining My Voice requires an invitation. Contact Brian Burrows at [brianburrows@bellsouth.net](mailto:brianburrows@bellsouth.net) or Matt Haynes at [mchaynes14@yahoo.com](mailto:mchaynes14@yahoo.com) to have an invitation sent to you. The online registration is simple to complete, the website is easy to navigate, and it's free.

## School Word Search

ADVISORY	GRADES	PHYSICS
ART	GYM	READING
BACKPACK	HISTORY	REPORT CARDS
BOOKS	HOMEROOM	SCIENCE
BUS	HOMEWORK	SOCIAL STUDIES
CHALKBOARD	HONOR ROLL	SPANISH
CHESS	LIBRARY	SPEECH
COMPUTER	LUNCH	SPORTS
DESK	MARKERS	STUDENTS
DRAMA	MATH	STUDY
ERASER	MUSIC	TABLE
ESSAYS	NURSE	TARDY
EXAMS	OFFICE	TEACHER
EXIT	PAPER	TEAM
GERMAN	PENCIL	TEST

N	U	R	S	E	D	A	R	G	N	I	D	A	E	R
S	E	I	D	U	T	S	L	A	I	C	O	S	E	E
H	T	A	M	O	O	R	E	M	O	H	U	P	X	S
I	T	N	K	C	A	P	K	C	A	B	O	A	A	A
S	R	E	E	H	O	M	E	W	O	R	K	N	M	R
T	E	R	A	D	S	P	O	R	T	S	P	I	S	E
O	P	E	G	M	U	S	I	C	I	P	H	S	R	H
R	A	T	E	S	G	T	A	T	X	E	Y	H	E	C
Y	P	U	R	Y	R	S	D	E	N	S	C	K	A	
R	C	P	M	A	D	E	S	K	V	C	I	N	R	E
A	H	M	A	S	T	A	B	L	E	I	C	U	A	T
R	E	O	N	S	B	O	O	K	S	L	S	L	M	A
B	S	C	I	E	N	C	E	C	I	F	F	O	A	R
I	S	P	E	E	C	H	A	L	K	B	O	A	R	D
L	L	L	O	R	R	O	N	O	H	S	T	U	D	Y



## CRS Parent Connection

Children's Rehabilitation Service  
Alabama Department of Rehabilitation Services  
602 S. Lawrence St.  
Montgomery, AL 36104

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Montgomery, AL  
Permit No. 109



## What's Ahead

- March 17, 2009** *Parent Leadership Academy*, sponsored by the Alabama Network for Children with Disabilities, Alabama Parent Education Center, 10520 U.S. Highway 231, Wetumpka. Participants must attend all three sessions – 9 a.m. to 4 p.m. March 17, March 18, and April 18. Register by March 10. For more information, call (334) 567-2252.
- March 22-28, 2009** The *seventh annual "Cover the Uninsured Week"* will take place in cities and towns all across the country.
- March 28, 2009** *Individualized Education Program (IEP) Workshop* presented by Alabama Parent Education Center and "Making Connections," Faith Presbyterian Church, 5003 Whiteburg Drive, Huntsville, 3 to 4:30 p.m. Free for parents, caregivers, and others to assist in the understanding of their child's IEP. For more information, call (866) 532-7660 by March 20.
- June 7-11, 2009** *Alabama Governor's Youth Leadership Forum*, Troy University. For more information, contact Becky Fields at (251) 479-8611.
- June 24-26, 2009** *Alabama Disability Mega Conference*, sponsored by The Alabama Council on Developmental Disabilities (ACDD) and Alabama Association for Persons in Supported Employment (AL-APSE), Montgomery Renaissance. For more information call, AL-APSE at (334) 353-7713 or ACDD at (334) 242-3973.
- Oct. 9, 2009** *Spina Bifida Conference, "Bridges to Independence,"* sponsored by the Spina Bifida Association of Alabama and The Children's Hospital (TCH) in Birmingham. For more information, contact Betsy DeCesare at (205) 939-5281, Betsy.DeCesare@chsys.org or Angie Pate at (256) 295-0757, angie.pate@gmail.com.

**Local PAC meetings:** Check your local CRS office for dates and times of meetings in your area.



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